Including People with Developmental Disabilities as a Priority Group in Canada's COVID- 19 Vaccination Program: Key Considerations: Part 1

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Background

I. Purpose

This document presents evidence to policy makers to support the inclusion of adults with developmental disabilities as a priority group in Canada's COVID-19 vaccine distribution plan.

The purpose of this document is twofold:

- First, this document outlines reasons <u>why</u> adults with developmental disabilities and those who support them, including family caregivers, must be prioritized in vaccine distribution. It has been informed by research from Canada and other jurisdictions, as well as vaccine prioritization policies from other countries, which have considered this population in the early stages of their vaccination programmes.
- Second, this document offers considerations for <u>how</u> vaccines can be promoted and administered to people with developmental disabilities through accessible information and accommodations.

II. Key Messages

People with developmental disabilities should be prioritized in Canada's COVID-19 vaccine distribution plan. As a group that has been repeatedly overlooked in Canada's pandemic response, it is critical to include adults with developmental disabilities as a vaccine priority group, in accordance with Canada's public health ethics framework on COVID-19.¹ Moreover, relevant public health, policy, and political decision-makers should prepare to make vaccine deployment accessible for adults with developmental disabilities, along with the people who provide care for them.

Key considerations include the following:

1. Why prioritize people with developmental disabilities?

- a. Higher risk of COVID-19 related morbidity and mortality in developmental disabilities;
- b. Implications of existing public health measures to protect and support people with developmental disabilities.
- **2.** How can Canada deliver the COVID-19 vaccine to people with developmental disabilities in accessible ways?
 - a. Remove barriers to support people with developmental disabilities in Canada's vaccine distribution/administration plan;
 - b. Offer easy read vaccine information to communicate the safety (benefits and risks) and efficacy of vaccines, address misinformation and vaccine-hesitancy.

III. Federal Vaccination Prioritization in Canada

The National Advisory Committee on Immunization (NACI)² is tasked with providing a framework for vaccine allocation in Canada. While other countries around the world (see Appendix A) have explicitly underlined how people with disabilities, including developmental disabilities, are included in their plans, Canada's national and many of the provincial frameworks have not yet mentioned prioritizing this atrisk group or their caregivers, regardless of whether or not they live in congregate settings or elsewhere.

Vaccines - Why?

1. COVID-19 related morbidity and mortality in developmental disabilities

Although Canadian data on COVID rates or outcomes for people with developmental disabilities is scarce, it is known from studies in other jurisdictions that adults with developmental disabilities are at greater risk of contracting COVID and dying from the virus.^{3,4} Since Canada is lacking COVID-related data amongst this population, and prioritization frameworks adhere to evidence-based methodologies, it is important to understand the data that are available from other contexts. In fact, current figures actually underestimate the heightened risks associated with COVID for people with

developmental disabilities.^{3,4} Adults with developmental disabilities are four to six times more likely to die from COVID than other individuals, indicated by a major UK report that reviewed deaths due to COVID.³

Age, place of residence, and comorbid health conditions are powerful factors to consider when understanding who is at greater risk if they contract COVID-19. These have been <u>highlighted in federal guidance about vaccines in Canada</u> but not in relation to developmental disabilities specifically.

Age: Federal vaccine prioritization has identified older adults as a target group. It is important to recognize that adults with developmental disabilities show signs of <u>frailty at ayounger age</u>⁵ and are almost four times as likely to die prematurely in comparison to other adults.⁶

Reports of COVID-related deaths in those with developmental disabilities show the greatest proportion of deaths among middle-aged adults with developmental disabilities, in contrast to higher risk of mortality for older adults in the general population.^{3,6,7} Although the overall number of COVID-19 deaths in young adults with developmental disabilities is lower in comparison to middle-aged and older adults with these disabilities, the risk of death among young adults with developmental disabilities is up to 30 times greater than the general population (where deaths in young adulthood are extremely low).³

Residence: People who live in congregate care have also been prioritized in federal vaccination planning. However, congregate care does not necessarily include people living in group-based community living and definitions of these settings vary by province or territory.

Research from other jurisdictions⁸ indicates that adults with developmental disabilities in care homes are more likely to die from COVID-19, ³ and that the larger the setting, the higher the risk of mortality. ⁴ In part, the heightened risks in mortality are related to the number of residents and workers in those settings, however, other factors may also play a significant role. More specifically, it is also likely related to the age, disability severity, and medical complexity of residents, who require more extensive hands-on care.

However, it is not only the individuals who live in larger congregate care settings who rely on physical contact with others to support their daily life activities. Many live independently or with family and receive a combination of informal and formal support in their home from relatives and paid staff, or they live with roommates with developmental disabilities, who also rely on paid staff to help them with their daily activities. Not only are caregivers able to transmit COVID to the person with a disability under their care, but they are at risk of getting ill themselves, resulting in critical caregiving gaps. A loss of a known, preferred caregiver presence (family or paid) has significant health risks, in addition to being disruptive for the individual. It is crucial that the people responsible for providing hands-on care to individuals with developmental disabilities are protected from contracting COVID, to protect themselves, to prevent a shortage of care staff, to mitigate the transmission of the virus to other care workers across care settings, and to prevent at-risk populations, such as adults with developmental disabilities, from contracting COVID.

Comorbid health conditions: NACI has identified people with high-risk clinical conditions to be included as a priority group for vaccination,² noting that the evidence for which high-risk clinical groups should be included will evolve over time. However, Canada's federal guidance does not list the actual clinical conditions to be included, nor is disability explicitly mentioned.

It is important to note other jurisdictions' vaccination prioritization documents identify the harms of high-risk conditions that occur more frequently in people with developmental disabilities, such as diabetes, obesity, chronic respiratory disease, severe mental illness and neurological conditions.

In a UK population based study⁹ adults with Down syndrome were more than four times as likely to be hospitalized for COVID, and more than 10 times as likely to die as other adults, after adjusting for other contributors such as cardiovascular and pulmonary diseases, dementia, and whether they lived in a congregate care setting. Other conditions associated with mortality in people with developmental disabilities include severe to profound intellectual disability, epilepsy, mental illness, dysphagia, dementia, mobility impairments, incontinence, skin conditions, constipation and sensory impairments. For those with these underlying conditions, it not only exacerbates the harm of COVID-19 on their health and well-being, but their risk of transmission is also increased due to the necessity of in-person health care for such conditions.^{10,11}

2. Implications of existing public health measures for people with developmental disabilities

As a result of public health measures throughout the COVID-19 pandemic, people with developmental disabilities have experienced greater isolation and restrictions

than other groups, which continues to have detrimental impacts on their health. Due to cognitive impairments, many are less able to understand why restrictions are in place, and less able to adapt to other ways of interacting with others (e.g., working from home, meeting with friends and family virtually, using technology).^{12,13} While the complex public health restrictions can make it difficult for adults with developmental disabilities to protect themselves from the virus, they also pose serious hindrances to their mental health.

The dramatic changes in day-to-day life due to the pandemic have had serious impacts on the mental health of adults with developmental disabilities,^{12,14} and have also significantly affected their families¹⁵ and the paid staff supporting them.¹⁶ This has only worsened since the onset of COVID-19. Canadian self-advocates have highlighted mental health as their greatest concern,¹⁷ which is echoed in research with Canadian families.^{18,19,20} In an <u>Ontario survey</u> ¹⁶ of almost 900 direct support staff, 75% reported worsening mental health and 62% reported increased aggression in the people with developmental disabilities who they were supporting due to the pandemic. Disruption to daily routine, social interaction, employment, leaving their residence, and participating in other activities can be extremely difficult for individuals with developmental disabilities. Prior to the pandemic, mental health disorders were already the most common health issue experienced by these individuals, coupled with few mental health supports available.¹³

Moreover, when someone with a developmental disability is exposed to COVID-19, it can be difficult for them to comprehend or follow isolation procedures, without major mental health consequences.²¹ This also poses a significant public health risk to the people around them. For example, the required two weeks of self-isolation due to a potential COVID-19 exposure or infection for someone who cannot understand why this is occurring is extremely distressing and sometimes impossible, especially when that person lives in a group setting and needs to be restricted to their room or one section of the house. Accordingly, prioritizing vaccine distribution for adults with developmental disabilities will provide an additional layer of protection to enable people with developmental disabilities to engage safely with others and continue to receive health care and other services that are vital to their livelihood.

Vaccines - How?

This section highlights a series of action items that are necessary to ensure that adults with developmental disabilities are successfully included as a priority group in Canada's vaccine planning, and underscores the feasibility of doing so. Foremost, Canada's vaccine distribution plan must integrate an equity lens, with a focus on disability inclusion and accessibility. The inclusion of such accommodations will also be helpful to other groups who may also experience difficulties understanding information about vaccines or participating in stressful group-based inoculation procedures. Evidence for this section is based on prepandemic health care guidance and efforts from other jurisdictions.

1. Vaccine distribution plan: How to achieve accessibility

Throughout the COVID-19 pandemic, the media, public health surveillance, and research have paid little attention to people with disabilities.²² Policy responses to the pandemic must strive to mitigate the harms of the virus on all people in Canada. To achieve this successfully, and to avoid perpetuating pre-existing inequities for people with disabilities, Canada must ensure that where and how vaccines are delivered are accessible to all people with developmental disabilities and their caregivers. This includes attending to accessibility needs, along with considerations to mitigate the psychological harms associated with vaccination.

Vaccine administration: The importance of environment

For individuals with disabilities, the environment where the COVID vaccine is administered plays a significant role in minimizing potential barriers. Whereas some individuals will be able to travel to a vaccine centre, there are many individuals who, due to difficulties with following public health guidance (e.g., wearing a mask, maintaining physical distance), mobility issues, or extreme anxiety in unfamiliar settings, may require special considerations, adaptations, and accommodations. Consistent with federal guidance on accessibility of health care for people with disabilities during COVID and strategies to adapt COVID testing procedures,²³ similar efforts are required to ensure that vaccination centres and processes are accessible.

An accessible vaccine distribution plan can mitigate inequities experienced by adults with developmental disabilities by including considerations such as^{24,25,26}:

• Accessibility of physical environment (parking, clear signage, ramps, doors, lighting and noise);

- Training of people administering vaccines in working with people with developmental disabilities;
- Adaptations with regard to time of day, wait time, and length of time for inoculation session;
- Allowance for a support person and/or animal to be present;
- Option for vaccinations to occur in a more familiar and or/private setting;
- Opportunity to develop tailored plans for people whose needs cannot be easily accommodated.

It is important that the people who have the most contact with the person with a disability also be vaccinated. Distribution plans should explicitly name these essential paid workers and family caregivers in their plans. It is also important that people who the individual is reliant upon for care have the option to receive the vaccine simultaneously so they can continue with their caring duties.

2. Accessible information

Accessible information is not only a human right, but also a critical consideration in fostering an understanding of public health emergencies amongst individuals with disabilities. Adhering to a disability inclusive approach, accessible mediums of information are vital for individuals with disabilities to know how to be safe, to recognize the importance of the vaccine, how to access support, and how to make sense of an intangible public health crisis, such as the COVID-19 pandemic.²⁷ For instance, some individuals who are frightened of needles may want to refuse the vaccine. The failure to develop and communicate accessible vaccine information to address these fears creates a significant barrier for adults with developmental disabilities to protect themselves from the virus.

Throughout the COVID-19 pandemic, the development of accessible health information has been scarce.²² At a government-level in Canada, vaccine-related information was not developed with people with developmental disabilities in mind, many of whom have low literacy skills in addition to limited health literacy. For people to make informed decisions about vaccinations, communication strategies that adhere to accessibility standards are required, both to help individuals with developmental disabilities understand the material, and also to help others to more easily explain this information to them.

There are a number of strategies and resources available to create more <u>accessible</u> and <u>effective COVID vaccine information</u>²⁸ including:

- Simplification of language/"easy read";
- Inclusion of photos to illustrate concepts and ideas;
- Inclusion of audio and video-based guidance for non-readers;
- Materials available in braille;
- Use of American Sign Language (ASL);
- Design using high contrast text and background, readable font style, large font size; Compatibility with accessible technologies (I.e., text-to-speech reading software).

In addition to these strategies, it is critical to collaborate with adults with developmental disabilities to create accessible vaccine information. Accessibility can be supported by encouraging conversations about vaccines between health care providers and people with developmental disabilities, and offering tools and resources to support these conversations. It is also important to consider some of the unique concerns and information needs of families of people with developmental disabilities, based on their knowledge of their loved one's health history, as well as the unique needs of the many workers in the sector who provide essential in-person care.

Conclusion

People with developmental disabilities are at greater risk of morbidity and mortality from COVID-19 in comparison to the general population and have suffered disproportionate consequences of COVID-related restrictions on their mental health and well-being. The COVID-19 pandemic raises both ethical and social justice issues for marginalized populations²⁹ and our response must be bound by Canada's public health commitment to reduce health inequalities³⁰ and adhere to ethical principles outlined in Canada's public health ethics framework on COVID-19.¹ The <u>World Health Organization's Values Framework</u>³¹ identifies the higher rates of COVID-19-related severe illness and mortality among systematically disadvantaged or marginalized groups as a key principle when prioritizing groups for COVID-19 vaccination. Given the available evidence discussed above, adults with developmental disabilities should be considered a high risk clinical group. Accordingly, they should be prioritized in vaccine allocation, as should the essential workers and family caregivers providing hands- on care.

Priority designation on its own, however, does not guarantee successful vaccination rollout. Jurisdictions across Canada should begin planning for feasible administration of an accessible vaccination program for this group, which includes

the development and dissemination of accurate information about vaccinations, tailored toward their learning needs. There has been limited public discussion about the health care needs of this vulnerable population; hopefully this document can facilitate further communication about these issues and lead to actions which will improve the lives of Canadians with developmental disabilities during the pandemic and beyond.

Appendix A

Global Approaches to Vaccine Prioritization and Developmental Disabilities

On a global scale, several countries have specifically included developmental disabilities or disabilities more generally in their vaccine prioritization efforts. The following is a list of these countries and plans (note that this is not an exhaustive list, and priorities across the world continue to evolve with new evidence). Please visit https://www.hcarddcovid.com/info for more information and resources on COVID-19 and developmental disabilities.

- UK: Priority groups for coronavirus (COVID-19) vaccination: advice from the JCVI, 2
 December 2020
- Germany: Vulnerable people first: Government presents order for corona vaccinations
- Sweden: Everyone over 70 is next in line for a vaccine against covid-19
- Netherlands: Approach to corona vaccination in the Netherlands
- Australia: <u>Australia's COVID-19 Vaccine National Rollout Strategy</u>
- EU: Overview of deployment plans and strategies for COVID-19 vaccines
- US: <u>States Plan for Vaccinating their Populations against COVID-19</u>
 - New Jersey: <u>New Jersey's Phased Approach to COVID-19 Vaccination: Phase 1A</u>

New York: Coronavirus Guidance: COVID-19 Vaccine

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